

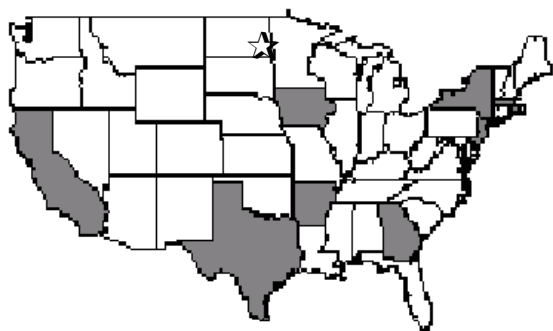
The Texas Birth Defects Research Center

Birth defects occur in one out of every thirty-three births. They are the major cause of infant mortality in the United States, and account for \$8 billion each year in direct and indirect costs. Yet, we do not know what causes two-thirds of birth defects and thus cannot find ways to prevent them.

It is time to change that. When we do know ways to prevent birth defects--like taking folic acid to prevent anencephaly and spina bifida--further research can help us evaluate and improve our public health programs.

Since October 1996, the Centers for Disease Control and Prevention (CDC) has maintained a cooperative agreement with the Texas Department of Health to enhance population-based research and evaluation of birth defects in Texas. This agreement created the Texas Birth Defects Research Center (TBDRC), one of eight such Centers of Birth Defects Research and Prevention in the nation.

Each Center is made possible by an existing population-based registry of birth defects.



Centers of Birth Defect Research and Prevention are located in Arkansas, California, Georgia, Iowa, Massachusetts, New Jersey, New York, and Texas.

The **Texas Birth Defects Registry** is administered by the Texas Birth Defects Monitoring Division (TBDMD) of the Texas Department of Health (TDH). TBDMD staff routinely visit hospitals and

other places where children are born or receive medical care. Information relevant to birth defects is collected, processed, and analyzed by a team of surveillance specialists, data quality staff, computer specialists, clinical geneticists and epidemiologists. (Strict procedures are followed to ensure complete confidentiality of the data). Once in the Registry, a case infant's family may be invited to participate in one of the Center's ongoing research studies.

Research includes the National Birth Defects Prevention Study and several other studies based on the Texas population. Members of the Texas Department of Health Institutional Review Board (IRB) annually evaluate the protocols for each study to protect the privacy and other concerns of participants.

Interviews are conducted with cultural sensitivity and can be done in either English and/or Spanish.

National Birth Defects Prevention Study

The *National Birth Defects Prevention Study* (NBDPS) will complete one-hour computer-assisted telephone interviews with more than 16,000 women across the nation over five years. About 12,000 of the women interviewed will have had children or pregnancies affected by birth defects. An additional 4,000 interviews will be with women who are mothers of infants with no birth defects.

Each family in the study will also be invited to donate swabs of cells from inside their cheeks. We will extract the DNA from their cells to study the genetic factors associated with birth defects.

All eight Centers are conducting identical interviews and genetic tests and will contribute these data to the CDC for analysis. By conducting the same study with such a large population in so many areas of the United States, the CDC and research collaborators have a unique opportunity to study the causes of many rare

defects, and to examine more common defects in greater depth.

Texas-Based Research Studies

The Texas Birth Defects Research Center conducts other research studies to discover the causes of specific birth defects or to enhance the surveillance or prevention of birth defects.

The *Study of Hispanic Origin, Maternal Obesity, and Disorders of the Central Nervous System* examines the metabolic-genetic-environmental risks associated with certain birth defects of the brain and spinal cord. It consists of a brief telephone interview and the analyses of biological specimens of 300 families of affected and unaffected infants. Proposed date of completion is 2001.

The *Drinking Water Disinfectant Byproducts Study* investigates the relationship between chemicals formed from water disinfection and several types of birth defects. Proposed date of completion is 2001.

The Texas Birth Defects Research Center partly funded components of the *Texas Neural Tube Defect Surveillance and Intervention Project*. The components use novel approaches to find causes of neural tube defects (NTDs), including anencephaly, spina bifida or encephalocele. One approach uses Geographic Information Systems (GIS) to construct residential maps of affected and unaffected infants to study the proximity and exposure to pesticides and toxic sites. Another approach examines the biological specimens of families to discover genetic and environmental factors related to NTDs. The proposed completion date is 2000.

The *Extent and Impact of Prenatal Diagnosis in the Two Pilot Regions of the Texas Birth Defects Registry* evaluates the number and type of prenatal diagnoses assigned to birth defect cases and surveys providers of prenatal diagnostic services for selected areas of Texas. This study was completed in 1998.

The *Texas Women's Health Survey* is a telephone survey of 1275 women. It examines women's awareness and consumption of supplements

containing folic acid, and their attitudes and knowledge about preventing birth defects. This study was completed in 1997.

Blood Folate Level Survey of Nonpregnant Texas Women is a survey of the folic acid consumption and blood levels of Texas women. The proposed completion date is 2000.

The *Neural Tube Defect Recurrence Prevention Study* is a statewide educational intervention for families with infants affected by neural tube defects. Its purpose is to reduce the risk of subsequent NTD-affected pregnancies. The proposed completion date is 2001.

The objectives of the *Neural Tube Defect Occurrence Prevention Study* are to evaluate and increase provider awareness about folic acid and the prevention of neural tube defects, and to establish this prevention message as a standard of care for all women of childbearing age. The proposed completion date is 2002.

Mortality Among Cases in the Texas Birth Defects Registry evaluates the patterns of survival of infants with different types of birth defects. This study links birth and death certificates to Registry records. The proposed date of completion is 2000.

For More Information

Mark Canfield, Ph.D., Co-Principal Investigator
Peter Langlois, Ph.D., Co-Principal Investigator
Dawna Wright, MPH, Project Coordinator
Texas Birth Defects Research Center
Texas Birth Defects Monitoring Division
Bureau of Epidemiology
Texas Department of Health
1100 West 49th Street
Austin TX 78756
Phone 512-458-7232
Fax 512-458-7330
dawna.wright@tdh.state.tx.us



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